Issue 37
December 2024

CENTRE OF EVIDENCE BASED DERMATOLOGY (CEBD)

Patient Panel Newsletter

www.nottingham.ac.uk/dermatology

Updates from CEBD

- We're really pleased to let you know that the ACNE ID study has opened to recruitment and has recruited it's first patients. This study is investigating different dosing strategies of isotretinoin for the treatment of severe acne in young people. Many thanks to the CEBD Patient Panel members who have helped to shape this study over the past couple of years including Irene Soulsby and Grishma Ramesh who have both been closely involved.
- Great news—the next CEBD Patient Panel meeting will be a full day, face to face meeting. It's taking place on Saturday 10th May 2025 at Jubilee Conference Centre, Nottingham. Travel expenses will of course be covered and if you'd like to attend (and haven't let us know yet) or have any questions at all about the day, please get in touch. We're also happy to hear any suggestions you might have for things to cover on the day.
- Our CEBD impact report will be available in the New Year. Produced every two years, this report highlights the impact of CEBD research. Past copies are available on the CEBD website and if you'd like to receive a copy of the 23-24 report please just let us know.
- Colleagues at The Centre for Applied Excellence in Skin and Allergy Research (CAESAR) at Bristol University are looking for responses to their survey for the Priority Setting Partnership for Food Allergy in Children Research: https://app.onlinesurveys.jisc.ac.uk/s/socs/foodallergypsp . Please complete this if relevant and help spread the word and share with anyone you know who may be interested.

How often do you bathe? New findings from the Rapid Eczema Trials project say 'do what suits you best'

The Rapid Eczema Trials research project has been funded by the National Institute for Health & Care Research (NIHR). It aims to enable people with eczema to answer questions they have about how best to care for their eczema.

Those affected by eczema are often given conflicting advice when it comes to bathing, so this was a priority to look at. The Eczema Bathing Study was designed by people with eczema for people with eczema. You can watch a video of people talking about their involvement in co-designing the research here. The group involved decided to look at whether it was better for people with eczema to have a bath or shower weekly or daily.

To make a fair test, everyone was assigned at random to either have a bath or shower weekly (1 or 2 times a week) or daily (at least 6 times a week). They needed to take part for 4 weeks to give it enough time to see if it made a difference to their eczema. 330 adults and 108 children took part and recorded their eczema symptoms weekly during the study.

Overall, the Eczema Bathing Study found it made no difference to eczema symptoms if people had a bath or shower weekly or daily.

This is great news for people living with eczema. It means they can do whatever suits them. As one person who took part said 'people with eczema now have the freedom to choose how often to bathe'.

Please see here to read more or watch a short video explaining the study results.

The success of this study is a huge testament to all the patients and carers that were involved in the co-production group who designed the study including CEBD Patient Panel members Amanda Roberts, Tim Burton and Fiona McOwan.

If you have eczema and are inspired to get involved—please see the Rapid Eczema Trials website for more information. If you're interested in taking part in a study as a participant, we are currently looking for volunteers for the Photo Assessment of Eczema Study.

Health Economics: The cheerful face of dismal healthcare decision making

By Dr Matthew Jones, Assistant Professor in Health Economics, Centre for Academic Primary Care, University of Nottingham

In October 2024, there was yet another story in the media highlighting the refusal of another cancer drug – Enhertu – for the treatment of breast cancer. The governing body for the NHS, the National Institute of Health and Care Excellence (NICE) was quoted as saying that the "drug was too expensive to be funded by the NHS". Many have criticised this decision saying it's drastically unfair and that patients will die because of this. But how has this decision been made?

All healthcare systems practice "healthcare rationing", because the population as a whole needs more healthcare than is practically available. For some countries, e.g. the USA, this isn't a problem, as healthcare is restricted to those that can pay for it. Other countries like the UK (with the publicly funded NHS) choose a different approach on how to best allocate limited healthcare resources to maximise population health. This is where NICE (National Institute for Health and Care Excellence) comes in, with its purpose to improve health and social care in England by helping healthcare practitioners provide the best care to patients. Part of this remit is to assess any new healthcare technologies to determine whether the new drug/machine/procedure should be made available on the NHS.

Although NICE is the governing body, the actual decision process is undertaken by a committee, which includes doctors, patients, drug company representatives, statisticians, epidemiologists, and health economists. For example, the committee for evaluating Enhertu contained nine doctors, three health economists, three statisticians, two epidemiologists, two lay representatives, two public health consultants, two pharmacists, a nurse, and a drug company representative.

A key piece of evidence used in the assessment is the economic evaluation performed by the health economists. Of particular importance are the Incremental Cost-Effectiveness Ratio (ICER) and the probability of cost-effectiveness. The ICER represents the ratio of health gains over the sacrifice of resources.

The probability of cost-effectiveness shows the committee what the chance is that they are making the right decision, i.e. the chance that the new healthcare technology will improve health efficiently. Too low a probability of cost-effectiveness, and the committee may reject the new healthcare technology until better evidence comes forward.

Another term to be aware of in health economics is QALY—Quality Life Adjusted Year. This is an extra year of life weighted by it's quality. As a rule of thumb, we generally assume that if a new healthcare technology has an ICER of less than £20,000 per QALY, then it's seen as cost-effective. Anything over £20,000 per QALY is generally seen as being too big a sacrifice of resources for too little health gains.

In the case of Enhertu the committee noted that even under the most favourable conditions, the ICER was at least £30,000 per QALY which is much greater than the accepted £20,000 per QALY rule. Therefore the NICE committee found that Enhertu did not offer enough health benefits for the resources that would need to be sacrificed.

Health economics is frequently known as the cheerful face of a dismal science, and health economists often get the blame when new technologies get turned down "because they are too expensive". But it's important to remember that when we are looking at both costs/resources used and health benefits when making these decisions. The ultimate objective is to make healthcare in the UK as efficient as possible while maximising population health.

The approach used by NICE is not perfect, and there are many criticisms but it works for now. At least health economists are giving those who have to make these decisions (and they do have to be made) a chance that the choice they are making is the right one.

Wishing You All a Merry and Bright Festive Season

And a huge thank you for everything you do to support CEBD research activities.

Please note our office will be closed from Fri 20th Dec, re-opening Thurs 2rd Jan.